

# Engaging seniors with early dementia to improve awareness of and access to supportive community services: A pilot project in three areas of Eastern Newfoundland and Labrador

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## Introduction

Dementia devastates all aspects of life, including work, social relationships, day-to-day activities, and Quality of Life (QOL) for seniors and their families. There are approximately 8,666 people living with dementia in Newfoundland and Labrador (NL), a province with the fastest aging population in Canada, and this number is expected to increase to 14,486 by 2035.<sup>12</sup>

With appropriate support, individuals with early dementia can live at home longer, contribute in society and maintain a positive QOL.<sup>3</sup> Seniors with dementia indicate that support services are indispensable.<sup>4</sup> Although sources of support, including community services, aim to fulfill the daily necessities of this population there are challenges to their availability, delivery and uptake<sup>5</sup> placing more pressure on family caregivers and health care institutions.

## Goal and Objectives

Our long-term goal is to inform the development of resources and best strategies to support a sustainable action plan to enhance access to and uptake of supportive services for seniors and their partners/significant others living at home with early dementia in NL.

Specific objectives were:

1. To identify barriers and facilitators related to access and uptake of formal supportive services that are necessary to improve and sustain health and QOL.

2. To identify best strategies to support the development, implementation, and sustainability of an action plan to enhance access and uptake of supportive services to improve health and QOL.

2. To collaborate with the government of Newfoundland and Labrador in the development of a dementia action plan to facilitate awareness of and access to appropriate community supportive services for seniors living with early dementia and their caregivers.



Forget Me Not

## Methods

The research proposal was approved by the NL provincial Health Research Ethics Board (HREB).

Semi-structured interviews were conducted with:

- Individuals with early dementia (10 in St. John's and surrounding area; 3 in Bonavista area, 3 in Burin Peninsula and 3 in Carbonear area.
- Caregivers or significant others (10 in St. John's and surrounding area; 3 in Bonavista area, 3 in Burin Peninsula and 3 in Carbonear area
- Key informants (community health nurses, Social workers) from each of the 4 locations

Most interviews were conducted virtually because of COVID 19

Data were transcribed verbatim and analyzed using descriptive thematic analysis. Key themes were identified and contextualized using anonymous illustrations provided by participants.

Data were presented to the Dementia Action Council, Government of Newfoundland and Labrador to inform the development of the Dementia Care Action Plan 2023-2026.

The Dementia Action Council is comprised of representatives from government departments, regional health authorities, the Alzheimer Society of Newfoundland and Labrador, Memorial University, and individuals with lived experience.

The Department of Health and Community Services and the Dementia Action Council will oversee implementation of the Dementia Care Action Plan. Small operational teams may be formed to support implementation of specific initiatives and will report to the Council. The Council will also provide advice to the Minister of Health and Community Services on matters related to dementia.

## Results

Barriers to access and uptake of services included:

- Not knowing what services exist/how to access them
- Feeling that they were not old enough or ill enough to qualify for services
- Family doctors not taking it seriously. "No one understands"
- Lack of available services in their area
- Alzheimer's Society website not easy to navigate
- Lack of understanding. The Alzheimer's Association is not for me, "I don't have Alzheimer's disease"
- The healthcare system

Facilitators to access and uptake of services included:

- Family physician
- Alzheimer's Association
- Seniors' Resource Center
- Persistence
- The healthcare system
- Financial security
- Social services
- Family support

Best strategies identified included:

- Importance of ready to hand information
- Increased visibility
- Specialized care centers
- Better training for health professionals
- Easier access to community services
- Preferential treatment
- Having a navigator

The Dementia Care Action Plan (now in draft form) was developed to improve the supports and services that people need to live well with dementia, create change in perceptions about dementia, and to increase understanding and acceptance. Implementation will require a coordinated effort from government departments, regional health authorities, private service providers, community groups, communities and families to advance the actions outlined in this plan.

## Conclusion

In eastern NL there is currently a need for:

- Early access to a diagnosis for those living with dementia
- A multidisciplinary approach to care,
- Treatment with dignity, respect, and to be included as a part of society
- Clear care pathways that provide clear understanding of how to access supports as one's needs change over time
- Resources and information available to best inform patients, families and healthcare providers

Results of the study informed the development of the Dementia Care Action Plan 2023-2026.

The Dementia Care Action Plan will be implemented over a three-year time frame with short, medium and long-term actions.

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